Witness Name: Terrence Lewis
Statement No.: WITN0019001
Exhibits: WITN0019002 -
WITN0019005
Dated: 12 February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF TERRENCE LEWIS

I, Terrence Ronald Burch Lewis, born on GRO-C 1952, will say as follows:

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 August 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference. I am a retired accountant; married with two adult children. The Inquiry is separately aware of my address and date of birth.

2. I was infected with the Hepatitis C Virus (HCV) through a transfusion of 8 pints of blood in January 1974, documented in a handwritten medical note which I exhibit as WITN0019002. At the time of my infection I was working in a warehouse in Sheffield having recently graduated from Sheffield University in the summer of 1973. I collapsed at work and was taken by ambulance to the Sheffield Royal Infirmary where I was told I was "seriously anaemic". I was admitted to hospital for a period of between 1 and 2 weeks and the transfusion occurred in the early part of that period. The note recording the transfusion is dated 24 January 1974 so it must have taken place on or before this date. I have no specific recollection of the transfusion itself, but I do remember telling one of my work colleagues who visited me in hospital about my being anaemic so needing a massive transfusion. Hence, although I have no memory of the intended transfusion being discussed with me, I knew of it from an early stage.

3. Paragraph 3 of the Rule 9 request asks about infection as a result of a relationship with another person and does not apply to me.

4. I have no recollection of being informed of the risks of infection associated with a blood transfusion and feel sure that I would remember if I had been told and/or provided with written information of the risks.

4.1. Approximately one year after my infection I received a letter dated 6 January 1975 which I exhibit as WITN0019003. The letter informs me that a liver biopsy test showed that my liver structure was normal and that it was expected that I would enjoy perfectly normal health, whereas I had in fact been infected with HCV which went on to cause significant damage to my liver in later life. In relation to understanding why a liver biopsy test was undertaken some time later in 1974, months after my original admission, the full blood transfusion and the investigations to try and explain my serious anaemia, I recently requested and have carefully reviewed my personal GP records. They contain an August 1974 letter from the hospital to my GP at the time. Which mentions the idea of a liver biopsy, to try and shed light on why I was so ill at the beginning of that year. The records also contain the report sheet regarding my admission in December 2014 for the biopsy and the results obtained, which were all normal. I also applied for a copy of my personal records from the hospital, but that was more difficult as Sheffield Royal Infirmary was closed many years ago. Eventually. I received a clear e-mail response from someone within the Sheffield Teaching Hospitals Foundation Trust that an extensive search had not turned up any records for me. I was also advised of the NHS Code of Practice for the retention of standard health records, strongly indicating that my records would have been destroyed long ago. I have spoken in recent months with Ms Yvonne Dawes, the specialist nurse at the hospital in Guildford who treated my once my Hepatitis C infection had been established, further referenced in Paragraph 6.3 below. My conversation with Yvonne was helpful in many ways, not least in relation to the liver biopsy in 1974. She advised me that, as early as that year, there were no tests being carried out as a matter of course in relation to possible blood infections and that, of course, Hepatitis C was not properly identified until many years later. In Yvonne's view, because of the unexpected anaemia I experienced as a young and generally fit man of 22, and the largely unsuccessful attempts to identify the cause (for example no stomach ulcers were found, no history of anaemia was known in my family and so forth), the liver biopsy was probably undertaken to try and identify whether there was something functionally wrong with my liver, in view of its close association with the generation of red blood cells. Hence, I have no reason to believe that the liver biopsy was for any other purpose than as part of the investigation into my anaemia and need for the blood transfusion.

4.2. In 1976 I sought to donate blood but was refused because of my medical history. The National Blood Transfusion Service sent a letter to my GP, dated 5 July 1976, which I exhibit as WITN0019004. The letter states the reasons I was unable to provide a blood donation as, "a history of sudden collapse followed by blood transfusion in 1974", and requests provision of my clinical details to determine whether I could become a blood donor. I do not recall ever being advised that I

was unable to donate blood because of a risk of my being infected from a blood transfusion nor do I know whether the reason for the concern was because I had previously collapsed and/or the risk of infection. In order to try and obtain more certainty about the circumstances of the refusal to take blood from me, I reviewed my GP records and wrote to the National Blood Transfusion Service. The July 1976 reply from Dr Barclay summarises what he knew about my hospital treatment two years earlier and confirms that the late 1974 liver biopsy revealed no abnormality in my liver tissues at that time. In response to my recent letter to the transfusion service, I received a telephone call from one of their nurses called Sue. She explained that she and Dr Asghar had been very interested to read about my case and see the July 1976 letter sent to my GP, as it threw some light on the different procedures being used 40 years ago as compared with today. We discussed the fact that the website of the transfusion service indicates no blood will be taken from anyone who has received a blood transfusion or other blood products since the beginning of 1980, because of the risks associated with variant CJD, but that there is no blanket restriction in respect of earlier transfusions etc. I did not specifically mention my history of Hepatitis, but Sue informed me that bloods are always tested for a range of infections etc, before they are brought into the bank for use, and that this would include tests from hepatitis. Hence, in her and Dr Asghar's view, the most likely reason for my being refused when I offered to give blood in 1976 was the clear uncertainty as to why I had been so unwell two years previously. Hence, as with the detail given in paragraph 4.1, I have been unable to identify any evidence or likelihood of matters being covered up by the Health Service as to the possibility of contamination from the blood transfusion I received in January 1974. I remain confident that my own experience with the NHS, in 1974, 1976 as well as from 2008 onwards was perfectly straightforward and did not involve any cover up.

5. I was infected with HCV as a result of a transfusion of blood. To the best of my current knowledge, I was not infected with any other virus.

6. I became aware of my HCV infection as a result of a routine visit to my GP in 2007 for a sore throat. The contact with my GP and my diagnosis are documented in a letter of my GP dated 10 November 2008, which I exhibit as WITN0019005.

6.1. The circumstances were that in late 2007 I had a sore throat which persisted for a number of weeks and as a result I visited my GP in November 2007 who requested a number of tests. I do not know why my GP decided to request the tests and it may have simply been a combination of my age and the fact that I rarely visited my GP practice. A recent examination of my personal GP records provides no further useful evidence of the reason for various tests being requested by Dr Raj, other than to try and why I had a persistent sore throat. One possibility he considered was thyroid disease and I was referred to the local thyroid clinic in the spring of 2008, but the tests then undertaken did not reveal any particular problems in that regard.

6.2. The test results revealed that there was something wrong with my liver and I had further tests which confirmed my HCV infection.

6.3. I was then referred to the Royal Surrey County Hospital for treatment under the care of a consultant, Christopher Tibbs, and specialist nurse, Yvonne Dawes, who were both brilliant throughout. I also received counselling from Yvonne.

6.4. I was told that, although my liver was quite damaged (4/5 out of 6), my liver function was not seriously impaired. I was also told that if the condition was not treated it would lead to cirrhosis and possibly cancer.

6.5. I was told of the options for treatment and of the side effects of the recommended drugs, Interferon and Ribavirin. I was told that the course of treatment would last 48 weeks and it was hoped, on the basis of the hospital team's existing experience, that the treatment would be successful. I was also told that it would be tough and that the treatment was far worse than the effects of the virus.

6.6. I commenced the treatment (Interferon and Ribavirin) in mid October 2008.

7. Paragraph 7 of the Rule 9 request asks whether I was treated without knowledge or consent or without adequate information or for the purposes of research. I do not believe that I was.

8. In terms of the effects of my infection, between 1974 and 2008 (34 years) I was not aware that I was infected and as mentioned above, although my liver was damaged, its function was not seriously impaired. I now realise, however, that the tiredness and lack of energy I started to experience from around 2006 was attributable to my infection. I found over this period that I often needed to sleep in the afternoons and early evenings and this became a standing joke in my family. On one occasion I fell asleep while I was actually leading a bible study group; and on another I fell asleep while visiting the washroom of a restaurant. At the time I thought this tiredness was because I had a very busy life and was just getting older. However, as I am now aware that fatigue is a common symptom of the infection and I no longer feel anywhere near so tired following the eventual success of my treatment, I believe that my infection was the cause.

8.1. I found the treatment for my infection extremely difficult. Following commencement of treatment in 2008 my red cell blood count plummeted, and I struggled terribly with fatigue to the extent I found walking uphill or upstairs very hard. If I had to go upstairs in my house I had to plan and think about what else I might need to do while upstairs, or take downstairs with me, because I knew I wouldn't be able physically to make another journey within several hours. I suffered from shortness of breath and my legs ached.

8.2. In December 2008 I was prescribed EPO to help boost my red blood cell count, which I had to self-administer by injection.

8.3. I suffered from rashes and itching, on my face, chest and back from the Ribavirin, which caused me difficulty sleeping. I was referred to a dermatology specialist and prescribed medicine which helped. I also became grumpy and depressed.

8.4. As already mentioned I was told of the side effects, and I was also provided with literature. My consultant, Christopher Tibbs, described the treatment as similar to chemotherapy, with possibly matching side effects like hair loss.

8.5. In the initial stages of treatment I had check-ups weekly. This then reduced to every two weeks and then monthly.

8.6. By Spring 2009 the viral load in my body was undetectable, and I managed a 10K run in May 2009. I finished the treatment in September 2009 and at that stage the virus was also undetectable. However, at my 6 month test following treatment, in March 2010, the virus had come back with a vengeance. A second test (as a precaution against a rogue result) confirmed that the virus had returned, and I recall around this time that my wife noticed that my energy levels had dropped again.

8.7. My consultant, Chris, advised that there was no point trying Interferon and Ribavirin again because this combination had failed to clear the virus. He told me of a new US drug which had proved successful but which wasn't yet available in the UK. In October 2010 Chris referred me to a colleague, Graham Foster, at the Royal London Hospital in Whitechapel, on the basis that I might be a suitable candidate for a new drug trial. I attended the Royal London on 2 or 3 occasions and provided consent to be part of the trial but I wasn't selected.

8.8. The only complaint I have with the care and treatment I received over this period is that no-one ever got in touch with me to tell me what was happening and for 5 or 6 months after my last attendance at the Royal London I did not receive any information at all. Eventually, around the middle of 2011, I contacted Yvonne and Chris at the Royal Surrey Hospital who got in touch with the Royal London on my behalf and I was told towards the end of 2011 that I had not been selected for the trial.

8.9. I felt like I had been marking time for a year with no progress and the communication from the Royal London Hospital was poor (although Yvonne and Chris at the Royal Surrey were helpful as always).

8.10. NICE approved a new drug, Telaprevir, and in August 2012 I commenced a second 48 week treatment with a combination of Interferon, Ribavirin, and Telaprevir. The new drug, Telaprevir, was only prescribed for the first 12 months of treatment and had to be taken in tablet form four times a day together with a significant amount of fatty foods, such as milk, cheese, chocolate, butter, nuts and avocado, which I found quite difficult.

8.11. A counselling service was made available and they would ring me.

8.12. This time, although my red cell blood count dropped and was monitored, I did not need EPO. The rash re-occurred and I was prescribed the same medicine.

8.13. I found the second course of treatment worse than the first, particularly while taking Telaprevir, and I also suffered badly from haemorrhoids and became very cold, especially at night.

8.14. After 6 months of treatment the HCV virus was undetectable, as it was at the conclusion of treatment in July 2013. I had further tests in January 2014, January 2015 and February 2016 all of which were undetectable and this was described as, "compatible with cure".

9. I found the treatment physically debilitating and stressful, and between March 2010 and August 2012 I was effectively marking time while the new drug, Telaprevir, became available. I also found the news that my infection had returned in 2010 a big blow. GRO-C GRO-C She and my children were very worried by the whole experience. My children were not tested. My wife was required to undertake more of the work around the home and garden while I was undergoing treatment. We fostered children but were unable to do so while I was in treatment. I noticed little things like not being able to cut the grass. I feel my wife and children took the full brunt of my grumpiness and low mood and I know my condition was always in the back of their mind and a constant worry for them.

10. I have not personally experienced any stigma associated with the infection. I have been open about it with my close family, relatives, friends and employer.

11. From around 2001 I started to reduce my working hours (at first 4 days per week and then 3) and I retired as a tax accountant in 2010 to focus on fostering and other interests, in particular my church work and local politics. As a result I do not feel that I have suffered any adverse work-related or financial effects. In fact my employer was very understanding and allowed me to work from home.

12. I do not believe that I have received any other infections.

13. I describe the impact of my infection on my family in paragraph 9 above.

14. My clinicians, Chris and Yvonne told me of the availability of a financial support scheme when I was first referred to them for treatment and said that I would definitely qualify for a stage 1 payment. I applied to the Skipton Fund, was accepted and received £20,000 on 11 December 2008.

14.1. When my infection returned after the first course of treatment, Chris advised that my liver was getting worse and indicated that I was entitled, in his opinion, to a Stage 2 payment and regular annuity. I again applied, was accepted, and I received a £50,000 payment on 11

14.2. I believe I am also entitled to an income top up through the new EIBSS scheme of either £64 or £134 per month. My application for this award was accepted towards the end of last year, but I am still in correspondence with the EIBSS office to clarify the basis of the amount they are now paying and whether the level is in fact correct.

14.3. I personally have no complaints about the amount of financial support I received and continue to receive. I found the Skipton Fund, my GP and the clinicians, Chris and Yvonne at the Royal Surrey Hospital, very helpful through the process. However, I have heard that others in my situation have experienced difficulty and of some who have been refused support.

15. I have not experienced difficulties in obtaining treatment and care as a result of my infection.

16. As already mentioned counselling and support was made available to me and I found Yvonne, the specialist nurse, particularly helpful and supportive in this regard.

17.

18. **NOT RELEVANT**

Statement of Truth

I believe that the facts stated in this witness statement are true.

14 FEB 2019

Signed **GRO-C**

Dated 12 February 2019